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Framing Life as Work: Navigating Dependence and Autonomy in Independent Living

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Abstract

This paper offers an ethnographic account of the context of autonomy for participants at Moving Toward Independence in the Community (MTIC), an independent living program for adults with intellectual and developmental disabilities. In the case at hand, staff interventions are planned around goals, frame that increases temporal distance between the staff and participants by locating the object of action in the future. Similarly, suggestions establish social distance between staff intervention and participant action by placing the responsibility to act on participants. Together, goals and suggestions make up a larger interpretive frame that I call *lifework*, a method of explaining action that recasts dependence as work toward future autonomy. *Lifework* is a neoliberal frame that recognizes obligation as a legitimate part of adult life, normalizes the force society exerts on individuals, and interprets this force in daily life as "work." Other analyses of this neoliberal project highlight the work of institutions to remove people from dependency by changing their habits, practices, and frames of mind. This research often frames neoliberal projects of social control as a coercive force that subverts autonomy. This is not the case at MTIC, where I find that *lifework* is also an important symbolic mechanism for constructing autonomy. I show that autonomy is best understood as an ongoing and collaborative project to construct social and temporal distance around the individual. This project is both practical, preparing participants for action when they are alone, and ethical, a frame that is necessary for understanding autonomy amidst dependence.

Keywords Autonomy · Carework · Governance · Disability · Ethnography

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As part of an ongoing commitment to increasing the accessibility of my research, I work with a visual artist to create illustrations of my ethnographic research. You can find illustrations to accompany this paper at www.abagnallmunson.com.

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Introduction

Daphne[1] and Brendan arrive in a flurry for Brendan's semi-annual Individualized Service Plan (ISP) meeting;[2] Ari, Brendan's father is parking the car. Brendan is in a prickly mood, perhaps agitated from this morning's doctor's appointment and blood draw; perhaps bracing himself for this meeting. As Ari takes his seat, Martha passes a sign-in sheet around the table. The sheet collects signatures and positions: Kara, Program Specialist; Martha, Medicaid Service Coordinator; Latesha, Community Habilitation Worker; Daphne and Ari, parents; Adrianna, Researcher. When the sheet comes to Brendan, he fills in the spot next to his name, "subject of interest."

Martha begins with a general question, "What do you want to talk about today Brendan?" Brendan thinks for a moment before looking around the room for options, "What is there to talk about?" His parents translate for him, "What she is asking is how are things in the program." Brendan nods his head and offers a terse report on his recent social interactions, "Things are good. I made some friends." Kara elaborates, expressing her pride in Brendan's progress, "When he is at activities, he does socialize, its just hard for Brendan to make plans. I am proud of him for socializing. When he is at an activity, he isn't using his phone anymore. The next step is to plan something." Martha turns back to Brendan for a self-report on his attendance at activities, "I'm doing better."

Ari, distrustful of Brendan's track record of self-report, turns to Kara for a truer accounting. "He's doing better. He has missed a few times." She continues, elaborating on Brendan's recent interaction at activities. Last week, he arrived at dinner club with a cane in hand. He was tired and didn't feel well after walking 16,000 steps in the summer heat earlier that day. He collapsed on the couch for a break (at Kara's suggestion) but eventually left early because he was feeling dizzy. Agitated, Ari turns to Brendan, "Can you tell me what it is that makes socializing so hard for you? You might as well come home and sit in your room all day to play video games. When you are home you don't interact with anyone. Your brothers are home and you don't engage with them. You might as well go into a monastery and sit in a cell all day."

The room is silent. Brendan looks down at his hands, which are resting on the table, and refuses to answer. Daphne tries a softer approach, leaning toward him and placing her hand on his back, "You have to make the effort to be a part of a community. You have things you need to do. You need to eat right. You need to sleep right. You can't be taking 16,000 steps in a day. Especially when it is so hot like it was last week. You are going to get dehydrated and dizzy."

Brendan, his parents, and staff members have come together today to discuss, generally, Brendan's life, the progress he has made over the last six months toward a nebulous "independence." Brendan documents his progress (plans with friends, a movie night hosted at his apartment), which the group translates as failure (inadequate self-care, inconsistent attendance at activities). As the group searches for the root cause of Brendan's difficulties,

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[1] All names have been changed to protect the identity of my research participants.

[2] Brendan lives in a community for people with Intellectual and Developmental Disabilities (IDD), which I call Moving Toward Independence in Community (MTIC). The program is a community of 60 members who live in their own apartments in close proximity to one another in a small city in New York state. The program provides supportive services in participants' homes and the surrounding community. These include training in self-care, housekeeping, employment, self-advocacy, and social skills. Today's meeting is required by Medicaid to plan and coordinate the services and supports Brendan receives from his parents, job training staff, and MTIC. The Individualized Service Plan that results from this meeting is good for six months and is used as the template for billing Medicaid for the services Brendan receives.

they are communicating deeper messages about their expectations for Brendan's adult life. They long for Brendan to have community, an intrinsic motivation to socialize, and a productive life. If he is truly unable to do this, Brendan "might as well go into a monastery," isolated, unproductive, celibate. Daphne's softer approach highlights the routines of a normal adult life: self-motivation, engagement with a community, daily activity, wise decision-making, and bodily health. These metrics of adulthood stand in stark contrast to the realities of Brendan's disability, which is defined by the failure to achieve adult milestones like self-care, independent living, and gainful employment. They are also communicating a deeper message about Brendan's adulthood: that no one can do it for him. Adulthood requires self-care, a normal routine, and a concern for personal well-being, and self-motivated progress toward these goals is not optional. Daphne summarizes this, "*You* have to make the effort… you have things you *need* to do."

Staff at Moving Toward Independence in the Community (MTIC) are tasked with a peculiar mission, to provide support that enables participants in the program to live independently (more on MTIC in the Methods section). They do this by providing training in the activities of daily living, emotional support, and guidance in the formation of relationships. Their methods of intervention include a range of activities, from those typically associated with caregiving—cleaning, cooking, providing monetary support—to things like scrutiny, emotional support, encouragement, problem solving, etc. In this project[3] staff intervention and participant autonomy are in constant conflict. Brendan's desire to be an adult is a catch-22. While he and those around him interpret autonomy as a state of independence and self-motivation in daily life, Brendan cannot opt out of autonomy if he wants to be considered an adult.

The tension between intervention and autonomy is intrinsic to the project of supported adulthood, but it is also common to many other situations in modern life, especially those in which adulthood is seen as incomplete (Shanahan 2000; Chen and Kaplan 2003; Osgood 2005; Silva 2012). While a rhetoric of autonomy idealizes the isolated individual, the autonomous person cannot be removed from the society in which she lives. Autonomous citizens and their choices are shaped by the world around them. In other words, autonomy is possible (for everyone) only because it is supported. At the same time, opting out of societal expectations for autonomy is impossible and so theories of autonomy and neoliberal governance must grapple with this tension.

At MTIC, the obligation to autonomy is communicated to participants as their "job" or their "work." This characterization is ingrained into the participants' own understandings of their everyday lives. Colton described this quite aptly as he responded to the coaxing of his program specialist, Elizabeth, to sweep up some birdseed that had fallen to the floor while he cleaned his birdcage: "I know work is important, but sometimes I wish someone would do it for me… we all wish we had a butler."

Framing life as work is generally interpreted as a neoliberal project of imposing a work ethic on the recipients of social programs, transforming them into self-governing and self-disciplined (i.e. autonomous) subjects of the state (Foucault 1975; Rose 1992; Levinson 2010; Drinkwater 2015). Most of this research argues that neoliberal institutions aim to remove people from a state of dependency by changing their habits, practices, and frames of mind, ignoring ongoing dependencies intrinsic to daily life. At MTIC this is not the case. While the program seeks to increase autonomy, participants are not expected to escape dependence

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[3] Described elsewhere as *supported adulthood* (Ferguson and Ferguson 1993; Ferguson and Ferguson 1996).

altogether. In this context, strategies of neoliberal governance become interpretive strategies to manage the tension between dependence and autonomy, not erase it.

At programs like MTIC the project of autonomy is complicated, in part because the types of staff intervention participants need in order to live alone often involve a great deal of intimate scrutiny. Complicating the issue further still is that autonomy and an intrinsic motivation to care for the self are the focus of these interventions. What I argue in this paper is that staff members draw on a repertoire of interpretive strategies to situate dependency in social and temporal context (Emirbayer and Mische 1998). Staff describe their work according to a dichotomy between support, which is professional and distanced from the actions of participants, and care, which is parental and intimately involved in a participant's daily life. To clarify the difference between their support and parental care, staff organize their work around goals and suggestions, in contrast to force and rules. Goals increase temporal distance between staff and participants by locating the object of action in the future, while suggestions increase social space by placing the responsibility to act on participants. Together, these strategies, make up a larger interpretive frame (Goffman 1974) that I call *lifework*, a method of explaining action that recasts dependence as work toward future autonomy. *Lifework* is both a practical and interpretive strategy that brackets care from the moment of autonomous action. By refraining from direct hands-on work, staff members increase their social distance from participants, requiring them to take on the tasks of daily life. Where there is tension between the scrutiny of their interventions and a participant's experience of autonomy, interpreting intervention in the context of the past and future increases the temporal distance between their actions. In contrast to other accounts of this neoliberal frame, which use the obligation to autonomy as evidence of social control, this paper illustrates how the strategy of *lifework* allows the participant to emerge as an autonomous actor in the midst of their dependence on others.

I begin my analysis of *lifework* by first reviewing the literature on autonomy, carework, and neoliberal governance, in which I argue that autonomy takes shape when action is interpreted to construct boundaries around dependence. After a review of my methods, I continue my analysis by first describing the dichotomy between support and care in more detail, highlighting its importance for creating boundaries between the work of staff and participants. I elaborate on these interpretive strategies of support by detailing their utility in creating temporal and social space between staff intervention and the moment of autonomous action. I conclude my analysis with a return to *lifework* as an interpretive frame for managing the tension between intervention and autonomy, a process that includes recognizing obligation as a legitimate part of adult life, normalizing the force society exerts on individuals and interpreting daily life as "work."

A Review of the Literature

Philosophical accounts of autonomy highlight the separation of the individual from the social forces around them and their capacity to make choices independent of outside influence. Some theorists question the importance of independence in the definition of autonomy and suggest that autonomy is "a coordinated repertoire of skills and capacities that enable each individual to fully realize" themselves (Mackenzie and Stoljar 2000, 17). These skills—"consideration," "evaluation," "scrutiny," and "choice"— are embedded in specific interactions, contexts, abilities, relationships, and institutions that shape the opportunities people have to both learn and exercise autonomy (Barclay 2000; Friedman 2000; Christman 2004; Anderson and Honneth 2005; Stoljar 2011).

Carework scholars also question the centrality of independence to the ordering of social life, showing that society's ability to identify independence involves rendering dependencies invisible to foreground the action of autonomous subjects (Rivas 2011). Because humans are embedded in social systems and formed through mutual dependencies on others, these scholars suggest that research focus on interdependence, a reframing in which "independence becomes a two-way responsibility and not solely an individual ability" (Reindal 1999, 364). These critical perspectives on carework highlight an enduring tension between choice (autonomy) and care (dependence), which assumes that the recipients of care are passive, while those who make autonomous choices are active (Mol 2008). These scholars argue that relational and structural arrangements shape capacity for choice, much as they do autonomy (Ho 2008; Mol 2008). Taking this seriously requires that we consider care as a set of practices shared within professional, familial, technical, and social support networks (Harbers 2010; Moreira 2010; Pols 2010).

At MTIC, the tension between dependence and autonomy is negotiated by framing the activities of daily life as work. Building on other research in this vein (Levinson 2010), I develop the concept of *lifework* to describe a therapeutic ethic that becomes hyper-visible in groups who are surveilled by the state. Framing life as work is generally described as a neoliberal strategy of social control that casts subjects of the state as therapeutic subjects (Foucault 1975; Rose 1992) for whom behavior is managed through self-government and self-discipline, not through punishment (Levinson 2010; McKim 2014). While Foucault and Rose describe these strategies of the self as a gentle form of intervention in comparison to techniques of the past, some scholars argue that neoliberal obligations to self-improvement are in fact mere extensions of the coercive projects of a punitive state (Schram et al. 2009; Soss et al. 2011; Drinkwater 2015).

Comparative research complicates these claims by showing that subjects of the state do not interact with the state as a macro institution but with smaller institutions that interpret the projects of the macro-level state according to localized interests and values (Haney 1996). As a result, people are socialized into different forms of self-government depending on the context of their interactions with state institutions. For example, McCorkel (2003, 2004) documents a historical shift in attitudes toward punishment in a women's prison. She attributes a dramatic shift in rhetorics of dependence to the state's wars on poverty and drugs. Similarly, McKim's comparative research shows that rhetorics of self-improvement differ in part by the funding mechanisms and commitment procedures through which clients access residential addiction treatment programs (McKim 2014).

Most of the research on neoliberal governance highlights the interventions of the state on "undeserving" dependents, especially those with mental illness, addiction, or those in the penal system. For these populations, dependence and reluctance to improve is presumed to be a choice (Estroff 1981; Brodwin 2013) and progress toward self-reliance a sign of success (McKim 2014). For example, when Haney's research subjects display a willingness to "work the program" or "take the bull by the horns," they demonstrate initiative and an interest in working on life (1996, 769–770). Programs like these often legitimate the authority of the state to discipline by appealing to the subject's failure to take control of their own lives, as when McKim's counselors tell clients that they are "mandated by life" to a treatment program (McKim 2014, 451)

Like these programs, MTIC uses progress toward independence as a marker of success and draws on normative expectations for self-discipline to legitimate their interventions. However, they do not mobilize these rhetorics in order to remove participants from dependency. Rather, the project in which they are engaged is to delineate which dependencies are justified by disability and which are the result of choice. Using *lifework*, staff interpret action (both theirs and that of participants) to construct boundaries around dependence and autonomy. In doing so, they place action in context, developing a common frame for planning, interpreting, and understanding action (Goffman 1974).

Sociological theories argue that action becomes meaningful under description (Hacking 1999; Anscombe 2000) because it is embedded in social and temporal relationship to other people and their actions (Emirbayer 1997; Emirbayer and Mische 1998). This is especially true in systems of neoliberal social control where action, or lack thereof, is the focus of intervention and the criteria by which the state assesses dependence and autonomy. Because these systems are concerned with changing behavior, the orientation of action to those that occurred in the past, present, and future is especially important (Emirbayer and Mische 1998). While carework scholars have described the interpretation of dependence as a matter of pushing it to the background in order to foreground the autonomous actions of individuals (Barclay 2000, 58; Ho 2008; Rivas 2011), *lifework* is not just a method of obscuring dependence. Rather, it is an interpretive frame (Goffman 1974; Bourdieu 1997) through which staff establish social and temporal distance between their interventions and the moment of autonomous action on the part of the participant. In doing so, they define the participant as autonomous *amidst* ongoing dependence, not in spite of it. This interpretive frame is especially important for reconciling a deep irony about adult life, that participants are obligated to be self-motivated and autonomous.

Methods

MTIC is a supported living community for adults 21 and older with intellectual and developmental disabilities (IDD). The program is located in a small city in New York state where participants live in their own market-rate apartments. The program screens applicants based on interviews with family members and trial engagement in program activities. While there are few strict guidelines, the program requires that participants live without 24-hour supervision, manage their own medication, and be emotionally stable (free from significant mental health issues). Admission to the program is made on a case-by-case basis and a majority of those who choose to interview for the program are accepted. The few who are not admitted right away are often encouraged to reapply after they have acquired more experience living alone.

Each participant at MTIC has a Program Specialist, a licensed social worker or mental health counselor, with whom they meet weekly to discuss their lives and coordinate the support they receive. They are also assigned a Medicaid Service Coordinator (MSC) who works with them to apply for and manage public benefits (Medicaid, Supplemental Security Income or Social Security Disability Insurance [SSI/SSDI], food stamps, accessible transportation services, job support, etc.). Each participant receives at least four hours of direct support through Community Habilitation (ComHab) to learn life skills like cooking, cleaning, socialization, and travel.

While MTIC is a private program and is not certified by the NY State Office for People with Developmental Disabilities (OPWDD), roughly half of the 57 participants in the program are personally eligible for OPWDD services and Medicaid; some also receive income support through SSI/SSDI. Those who are not OPWDD eligible are most often disqualified because their disability is not considered to significantly impair daily life. Families pay privately for the program fee, which ranges from $10,000–15,000 per year. For eligible participants, ComHab (billed at $35/hour) and MSC services are paid for by Medicaid. Participants who are not eligible for OPWDD or Medicaid pay privately for ComHab and MSC in addition to their annual program fee. Given the costs of the program, a majority of participants are from upper-middle to upper-class families; those few families with lower incomes had support from wealthier family members and one participant had a trust fund from a medical malpractice settlement. At the time of my research, all but one participant was white and 60 percent were male.

This paper draws on 1.5 years of ethnographic research at MTIC during which I observed 30 staff meetings, 20 Medicaid Individualized Service Plan (ISP) meetings, and 109 meetings with adult participants and staff. In addition to these formal observation periods, I attended over 50 activities ranging from trivia night at a local bar, a knitting class I taught, a newspaper club, internships, classes, and a weekend trip to Williamsburg, Virginia. Most of my observations centered on the interactions between program participants and staff members, but I also conducted 38 interviews with parents and siblings and attended a handful of family events. While the content of these interviews is not directly engaged with in this paper, they have influenced my thinking and theorizing about the program.

This project was approved by both Columbia's IRB office and MTIC's agencywide ethics board for research. Because the program only admits relatively high functioning individuals, those capable of living their daily lives without supervision, Columbia classified them as able to give direct consent. In accordance with Columbia's IRB guidelines, all participants in the program were given a letter explaining the purpose of my research, which they reviewed with a staff member (I was not present). The letter contained a consent form on which participants could indicate whether or not they wanted information about them to be included in my fieldnotes or other writing. MTIC's review board required that I also provide parents with a similar letter. Three parents and six participants indicated that they did not want to be included. In cases where there was a discrepancy in consent (i.e. parents wanted to be included and participants didn't or vice versa), I deferred to the desire of the participants. In all, I excluded six participants out of 57. In addition to the initial consent process, I adopted a practice of continuous consent through which I reminded participants of my research interests and asked permission to attend any meeting in which they were the singular focus.

My access to the program was brokered by staff and I spent little time alone with participants. Practically, this means that my observations of the standpoint and perspectives of participants in the program are filtered through a staff lens. In my time alone with staff, we often joked about how we wished we knew what happened when we were not present, "Oh, to be a fly on the wall." Still, I made a conscious effort to attend nonclinical activities—social gatherings, drop-in hours at the community center, day trips, a running group—which afforded me "one-on-one" time with participants under the distanced eye of a staff member.

During my observations, I took detailed fieldnotes in small spiral notebooks, which I then transcribed into long-form narratives. In addition, I made periodic memos on themes that emerged over my time in the field. Fieldnote data was hand-coded in Atlas.ti according to these themes and others that emerged during the review process. *Lifework* was the first and most consistent theme that appeared in my fieldnotes and memos, indicated simply by situations in which staff interpreted daily tasks in terms of obligation or employment ("job," "work," "need to," "have to," etc.). As I continued to analyze my fieldnotes, it became clear to me that this was one strategy among several that staff used to justify the common work of caring for participants, and so I also included instances when staff justified their direct interventions, especially those times when they resisted a description of their work as "care."

This paper places these justifications and interpretations in conversation to elaborate the tension between care and autonomy. In addition to my fieldnotes, this paper draws on close reading of Medicaid documents, program policies, and OPWDD guidance on the professional ethics of care.

I discovered MTIC through exploratory interviews on access to community services for young adults. Of the several programs in the NY area that I contacted, only MTIC responded to my request for an informational interview. In addition to sitting for an interview, the program director, Nancy, also connected me to several of the program's founding families who agreed to be interviewed. When I contacted Nancy six months later about conducting ethnographic research at the program, she enthusiastically welcomed me, hoping that my research might highlight MTIC's innovative approach to care. While the program is admittedly unique in a number of ways (i.e. the class status and racial composition of families and the private nature of the program), research with this population yields important insight into autonomy and disability more generally. The population served by MTIC clusters around a legal borderline designating OPWDD eligible individuals by their level of impairment. This provides a unique opportunity to research autonomy in a population for whom it is most contested by the state. It also illuminates breakdowns in autonomy that may otherwise be invisible in populations who are more or less dependent than MTIC participants.

Findings

Lifework as an Interpretive Frame

To say that *lifework* is an interpretive frame is to say that it is a strategy for explaining and sorting action. At MTIC, this process begins with defining the relationship of participants to others (staff, parents, the state, employers, other participants). For their part, staff at MTIC are trained to recognize and promote autonomy in all their work with participants. While care connotes dependence and deference to the authority of staff, support is closely tied to the work of independence. This professional imperative is driven both by OPWDD's institutional initiative to prioritize support over care and by MTIC's program design. OPWDD defines the work of competent professionals to support in direct contrast to care.

Staff support individuals to:

1. Live a life that is valued by the person as defined by their Personal Outcome Measures (POMs)[4] and not the personal values of the staff
2. Have more opportunities for desired community involvement
3. Think and problem-solve, helping them to figure out what they want to do
4. Learn new skills that increase their independence and decrease dependency on staff
5. Have increased self-esteem through positive interactions focusing on their abilities and not their disabilities (OPWDD training materials[5])

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[4] Personal Outcome Measures are assessed along seven dimensions of the relationship between support and independence: putting people first, building and maintaining positive relationships, demonstrating professionalism, supporting good health, supporting safety, having a home, and being active and productive in society.

[5] During my fieldwork, I participated in a new employee orientation during which we were introduced to OPWDD's *Core Competencies*. These observations come from my experience in the training but additional information is available at https://www.workforcetransformation.org/nys-dsp-core-competencies-resources/.

Drawing on these guidelines, staff explain and sort their interventions according to a strict dichotomy between support and care, reminiscent of the ritual separation of the sacred and profane (Durkheim 2001; Douglas 1966). To elaborate this distinction, staff frame care as a natural extension of parental intervention in a child's life characterized by a caregiver's intimate interest in the motivation behind action and their direct involvement in that action. By contrast, support is characterized by hands-off intervention driven by the participant's desires (Table 1).

I witnessed staff's commitment to support over care most poignantly when I visited Tyler at his apartment with his program specialist, Elizabeth. Tyler has an IT internship at a nonprofit where he is well-liked. The only thing standing in his way of paid employment is an IT certification. Having recently completed the related courses, Tyler needs to take the final exam. Today, he will register and sign up for an extended time accommodation. Elizabeth tries to ascertain what exactly is keeping Tyler from completing his application, "Do you need help, or do you just need to do it?" "I think I just need to focus on it."

Tyler retrieves his computer from the bedroom and navigates to the Pearson website. After the page loads, Tyler looks at the screen, moving the mouse around the page without clicking on anything. After almost a minute, Elizabeth interrupts, "Are you stumped right now?" Tyler doesn't respond and continues moving the cursor around the screen. "Okay, you should start by making an account." Instead, Tyler clicks a button to log in. Referencing a list of possible passwords, Tyler makes several incorrect log in attempts. Underneath the log in button are two options for activating an account and recovering a lost password. Tyler clicks on the activate account option and gets an error message; his account is already active. Elizabeth sits patiently beside Tyler, watching him navigate the screen, "Can I help you?" Tyler doesn't respond and Elizabeth doesn't push.

Tyler navigates back to his password document and makes a few more attempts to log in. Throughout an almost 10-minute process, Elizabeth offers a few quiet suggestions and guiding questions but is otherwise silent, hands in lap. Tyler moves through registration on his own for a few more minutes before pausing at a box asking for a rationale for his accommodation request. Tyler's hands are positioned on the keyboard as if ready to type but he doesn't move. Elizabeth suggests that he reference the doctor's notes he will submit with his application.

When Tyler leaves to get his file, Elizabeth glances at her watch and turns to me, "I have another meeting in like 20 minutes." When he returns, Tyler and Elizabeth work together to find two documents outlining his disability. "Do you know what you want to write or do you want to come up with something together?" Tyler pauses, looking up into his head, and thinks. "I can help you if you want." Tyler agrees to receive help before launching into his own rationale for his accommodation, "Due to my attention deficit disorder, it is reasonable to assume that I need more time to complete the exam." As he types Elizabeth offers help with spelling, "That's okay, my computer helps me."

Assuming that Tyler can scan the medical documentation on his own, Elizabeth begins to pack up, "I have a meeting with another participant. But I want to make sure you are comfortable before

Table 1 The Difference Between Support and Care

Support	Care
Hands-off intervention driven by the desires of the individual, characterized by a professional disinterest in the outcome of action.	A natural extension of direct parental intervention in which the caregiver is intimately invested in the outcome of action.
Intervention is offered in the form of *goals* and *suggestions*.	Intervention is offered in the form of *force* and *rules*.

I leave. If you are not able to do it on your own, I will come back afterward." Tyler nods his head but stares straight ahead at the computer, tears forming in his eyes as he moves the cursor around the page. Elizabeth stops packing and looks at Tyler, "Are you okay? Do you want me to stay? I can tell my next appointment I will be late." "I don't want you to miss your parking." "It's okay, I can fix that... what am I doing?" She unpacks her bags and resigns to stay until Tyler has finished scanning the documents without any intervention from her. By the time he has finished, Elizabeth is an hour late for her next meeting and has earned herself a parking ticket.

Elizabeth's interaction with Tyler is a painful but ideal example of support; she sits beside Tyler offering no direct intervention. She doesn't touch the computer and the advice she offers, Tyler ignores. Everything Elizabeth does elaborates Tyler's autonomous work: she asks permission to intervene, sits quietly until it is clear she is needed, and retreats to herself when Tyler refuses intervention. Even to the point of interfering with Elizabeth's next appointment, Tyler's work trumps Elizabeth's. From the beginning, Tyler admits that he doesn't need "help," rather he needs support if *he* decides he wants it.

In one sense, Tyler's life is the focus of both his and Elizabeth's work; however, understanding their actions towards each other as a common project puts Tyler's autonomy in danger because Elizabeth's actions begin to look like care: direct intervention in Tyler's action. By approaching Tyler with support, Elizabeth preserves a boundary between her job and Tyler's work, communicating that their shared project belongs to Tyler.

At first glance, the distinction between support and care seems easy to identify. The dichotomy, however, is a false one. Distinguishing support from care requires interpreting dependence along two dimensions, space and time. Take for example the question of hiring a cleaning service. When Aaron was new to MTIC, he struggled with enuresis, frequent night-time bed-wetting. Aaron would hide his soiled linen in his closet, causing his apartment and clothing to smell. An initial intervention was to hire a cleaning service five days a week. As he learned to clean on his own with ComHab, Aaron's cleaning service was reduced to three days a week. While it is clear that Aaron has made progress, staff surmises that he inappropriately relies on his cleaning service, ignoring his dishes and laundry when he knows they are coming the next day. At an ISP meeting, Aaron's program specialist shares her assessment of his progress, "So, I can't really tell your mom that you are keeping your apartment clean." "I know, I know I am doing this. I just get apathetic." Aaron and his staff attribute his reluctance to clean to lack of motivation. The cleaning service is an inappropriate intervention, care, because it promotes his dependence and impedes a deeper expectation that Aaron will take ownership of his work.

In contrast, when Tegan let slip that she and her roommate had hired a cleaning service, it was interpreted in a completely different light. Marilyn, her program specialist, recounted this at a staff meeting, laughing at Tegan's anxiety that staff would be upset. Both Tegan and her roommate work part-time and take classes at the local community college. After managing to keep up with cleaning for some time on their own, the women made the decision to split the cost of a cleaning service to give them more time to focus on work and school. Marilyn affirms Tegan's decision, citing her busy schedule, the fact that she is paying for it on her own (without the help of her parents), and that she made the decision without intervention from anyone else.

What distinguishes the nature of the cleaning service is the way staff interpret dependence. For both Tegan and Aaron, the social distance between the service and their obligation to keep their apartments clean is small; someone is directly cleaning for them. The temporal distance however is different. Tegan's cleaning service is interpreted as an appropriate support because it enables efficiency in her motivation to pursue other "work," education, and paid-employment. The service acts primarily on her pursuit of future autonomy. Initially, Aaron's cleaning service was also distanced in time from the object of action, that Aaron would learn to clean his apartment. As he progressed and learned to clean, the temporal distance between the service and the object of action decreased, and Aaron's dependence on the service was reinterpreted.

There is nothing inherent to a cleaning service that makes it support or care. Rather, the nature of action is constructed through interpretation and given meaning within the context of action. This process of accounting for action is a form of ontological politics in which autonomy is "brought into being, sustained, or allowed to wither away in common, day-to-day, sociomaterial practices" (Mol 2002, 6; Eyal and Hart 2016). The methods actors use to explain action are interpretive strategies through which they come to a shared understanding of the meaning of action, also called a *frame* (Goffman 1974).

Lifework is an interpretive frame that establishes distance between intervention and autonomous action by redefining dependence according to its social and temporal context. Ideally, interventions at MTIC will be both socially and temporally distanced from participant action. In cases when it isn't, staff interpret their work according to *goals* and *suggestions* because they maximize this space. Goals place action in temporal context by identifying the object of action as something in the future. As participants progress toward their goals, they are revised to reflect something further in the future. Similarly, suggestions increase social distance by placing responsibility for action on the participant and allowing them to interpret staff intervention according to their own desires. These interpretive strategies come together in *lifework*, a neoliberal frame that recasts dependence as work toward autonomy. Through this process of interpretation, the autonomous adult emerges as a self-motivated, independent actor in the midst of their dependence on others (Fig. 1).

Establishing Temporal Distance through Goals

While only half of the participants at MTIC are eligible for OPWDD and Medicaid, the standards set by the state shape the care provided to all participants. Under Section 1915 of the Social Security Act, the services MTIC provides are defined as Habilitation, services "designed to assist participants in acquiring, retaining and improving the self-help, socialization and adaptive skills necessary to reside successfully in home and community-based settings" (OPWDD ADM #2012-01). Habilitation Plans (ComHab Plans) outline staff's role in helping the person reach their "valued outcomes," or goals. There are four required sections of these plans: identifying information, valued outcomes, staff services and supports, and safeguards. ComHab Plans are used to both coordinate work between staff members and participants, and as a contractual record to obtain reimbursement from Medicaid[6] (Table 2).

ComHab plans coordinate activity as a contractual relationship between staff and participants. Through this, MTIC enrolls the participant in their own care by requiring their consent and participation in designing interventions, and by framing their activities as goals. Goals are a temporal and social frame that imagines intervention as distanced from a future moment of action and anchors staff intervention in the specific motivations of participants. The valued outcomes of the participant are always worded in the future tense (i.e. "Dana would like to learn independent meal planning"),[7] reflecting the expectation that participants desire progress toward independence.

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[6] For those who are eligible for Medicaid. Participants who are not eligible for Medicaid pay MTIC for their ComHab at an hourly rate of $35.

[7] OPWDD Administrative Memorandum- #2012-01: Habilitation Plan Requirements https://opwdd.ny.gov/sites/default/files/documents/ADM-2012-01.pdf

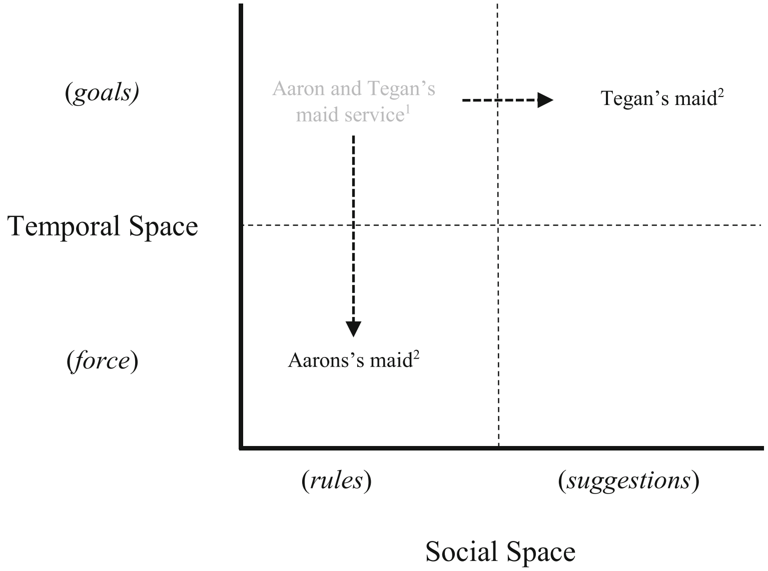

Fig. 1 Lifework as Interpretive Frame

At MTIC, valued outcomes are broken down into small, measurable goals with clear objectives: a desire to learn meal planning begins with making a grocery list to facilitate shopping. Goals are pursued, met, built on, and are ultimately the scaffolding for valued outcomes. Staff intervention in working toward goals emphasizes the supporting role they are meant to play. Staff will train Dana to make a grocery list, they will teach her to prepare healthy snacks, train her to cook, and assist her with labeling her meals for the rest of the week, but they will not do any of these things for her. More importantly goals are things to work toward in the future. Staff discussions about formatting goals center on the appropriate temporal expectations around action. Inappropriate goals are those that a participant can already do, can't be expected to accomplish, or those they won't or refuse to do. Goals are continually revised according to this temporal logic. Those areas of ongoing dependence, where a participant can't or won't work on a goal, are pushed to the background and removed from the context of *lifework*, "That can't be a goal; if you want the apartment to be clean, you need to get a cleaning lady." What is more, arranging action around goals also frames autonomy as a moving target; as a goal is met, a new one replaces it and daily life becomes a continual work in progress (Willhelm 1967; Dewey 2007). The following example illustrates the distinctions staff make between rules and goals.

Later in the ISP meeting that opened this paper, Brendan's parents and staff grappled with how to address a new hobby that they considered to be unsafe. One day last week, Brendan took a long walk along a riverside bike path past the county center, racking up 16,000 steps toward his FitBit competition with his mother and exhausting himself for a dinner group later that night. Brendan shares this at his ISP meeting as evidence of his growing independence and defends his predilection for long walks on the secluded bike path, "I was trying to crush Mom."

Kara, Brendan's program specialist, shares his parents' concern about his health and safety on such long walks and suggests that Brendan join MTIC's walking group on Thursdays. Brendan objects: "They don't go as far as I do." The group laughs nervously, and Daphne and Ari, Brendan's parents, respond with a "rule." "Okay, no more wandering past the county center unless

Table 2 MTIC Community Habilitation Plan

Community Habilitation Plan

Name:	Dana Smith	MSC:	Adrien Taylor
Address:	511 John Street, Apt 5	Medicaid #:	12345678
Review Date:	6/12/17	Plan Effective Date:	7/12/17
Frequency:	Weekly	Duration:	6 months
Location:	Home and other locations in the community		

Profile: Dana is a 28-year-old woman living independently in a one-bedroom apartment where she has been a participant in the MTIC program for five years. The program offers community habilitation, recreational and vocational support, and a 24-hour emergency phone. Dana works part time at a day care center where she has an employment counselor with whom she meets once a month.

Safeguards and Supervision: Dana knows how to dial 911 in case of an emergency and can evacuate her building in case of fire. She is able to ask for help in emergency situations and has access to the MTIC 24-hour emergency phone. Dana takes her medication independently. She checks in once a week with her father, who watches her take her medication over FaceTime and checks her medication box to make sure that her pills are sorted correctly.

Habilitation Activities and Goals:

Valued Outcome #1:	Dana would like to learn independent meal planning
Allowable service:	Training in general household management
Goal/Activity A:	To make a grocery list
Objective:	Make purchases at the grocery store that are based on an established grocery list
Staff action:	Staff will train Dana to make a grocery list based on meals she will make throughout the week
Allowable service:	Training in general household management
Goal/Activity B:	Dana will maintain a healthy diet
Objective:	Get into the habit of eating healthy snacks while watching TV
Staff action:	Staff will teach Dana to prepare healthy snacks to be eating while watching TV
Allowable service:	Training in general household management
Goal/Activity C:	Dana will learn to eat only the planned food for a particular day
Objective:	Portion control
Staff action:	Staff will train Dana to cook a variety of healthy recipes to be eaten throughout the week and will assist Dana with labeling the meal to be eaten on a specific day

you are with a group. You can do two laps if you are trying to beat me. That is a rule Brendan, do you understand?" Brendan defends himself, "I want to see the bridge," adding that he likes to walk along the path to take nature photography. "If you want to walk that far, go with friends. Use this as an opportunity to share your interests with someone who would enjoy them."

For Kara and Latesha, Brendan's ComHab workers, defending this "rule" is outside the jurisdiction of their work, as it threatens a carefully constructed distance from Brendan's autonomy. To preserve this distance, Kara and Latesha can only act on an ambiguous future, motivated by Brendan's own desires. Kara searches for a way to accommodate Brendan's desire for long walks in a goal, "Latesha and I can help you do this. We can break it down into steps 1, 2, and 3. We can make a plan, contact people, and help you follow through." Perhaps afraid that Brendan will interpret a plan as enough of a reason to go for a walk, Latesha adds, "But if no one else shows up, you can't go either."

The tension between his parent's rule and the staff's suggestions here is stark. While the rule, no walking past the county center alone, is a case-closed argument rooted in the specific knowledge of Brendan's walking route, staff's reaction is a little more nuanced. While his parents' rule offers some temporal distance in that it concerns something Brendan may do in the future, it collapses the social distance by inserting his parents' desires into the moment of action. Staff immediately begin to search for work-arounds, offering *suggestions* of alternative walking routes and formulating Brendan's desire to walk along the river as a *goal*. Suggestions and goals reestablish social and temporal distance by restoring ambiguity to the moment of action and deferring to the participant's desire for intervention. They also invite Brendan to take ownership of his action by appealing to his desire for improvement in socialization and the routines of a normal life.

When staff interventions are framed in relationship to goals, they are distanced from autonomy in that the focus of their work is always in the future, never here. In instances when intervention looks like care, staff describe their work in the context of a participants' past dependence and envision their work as acting on the future autonomy and progress of the participant. These justifications allow staff to negotiate the tension between scrutiny and independence because participants' temporary dependence is embedded in their future autonomy.

Normalizing Force with Suggestions

The adulthood of participants at MTIC is central to the support the program offers. Staff members appeal to the adult status of participants to encourage "appropriate" behavior and to frame the expectations the program has for them. Suggestions reflect this concern for adulthood by evoking the autonomy of participants to make independent decisions, but they do not come without the weight of authority. Suggestions are often intimate, concerning personal hygiene, cleanliness in the home, appropriate social behavior, or the daily rhythm of participants' lives. Even if they are not overtly forceful like rules, suggestions are disruptive. Staff manage this tension by normalizing their suggestions, appealing to the desire of participants to be perceived as adults and by softening their suggestions by taking them on themselves: "This is something I would do." This gives suggestions a sort of reciprocal nature: "You can be like me."

When Kara and I arrive at Mona's apartment one morning for her weekly meeting, she is worked up, unsure of whether she will be back in time for a doctor's appointment after visiting her parents this coming weekend. She begins to cry as Kara picks up the phone to call Mona's mother. While the phone rings, Kara reminds Mona, "We are adults, right? *Independent* adults. We can't cry at the drop of a dime."

Kara talks for a few minutes with Mona's mom before asking to see Mona's birth control blister pack. Mona's face contorts as she prepares to go get the pack from her purse, "I have a problem." She explains to Kara that she accidentally took a pill from a new pack and threw one away. It is unclear whether she threw away an old pack or her next one, Mona can't remember. Regardless, she produces a blister pack from her purse and gives it to Kara.

Kara narrates to Mona's mother, "Oh my, this is a mess." The blister pack has been used sporadically, there are two pills missing from the first week, three the next. Today's pill hasn't been taken. Kara's voice is urgent, concerned about Mona's apparent inconsistency. "Let me tell you something about myself, I take my pill first thing. I keep my pack by my bed, by my jewelry. I don't even take it with food. I just take it first thing, otherwise I would forget. Do you think you can do something like that?" Mona answers with a smile and a nod. Looking at the blister pack again, Kara suggests that an appointment should be made with the gynecologist while Mona is home because she is almost down to the brown pills, "Her period should start on Sunday or Monday." Mona nods her head, "I'm gettin' ready for it because I can feel it," Mona points to her hip, which always starts to hurt before her period comes. Kara nods her head, "Can you write down when your period comes? That's a good thing for all ladies to do."

The appeal to a normal adulthood here serves two purposes. On one level, Kara lifts the weight of her suggestions off of Mona by taking them onto herself and by placing their authority on all women, "That's a good thing for all ladies to do." In doing so, Kara establishes social distance between her intervention and Mona's action. Mona is obligated to take her medication as prescribed by her desire to be an independent adult, not because Kara wants her to. This appeal to adulthood is important to shift the burden away from Mona, but it also serves a practical purpose. Kara, Mona's parents and sister, and other staff members are not with Mona every day and are not present to administer her medication or to watch her take it. Appealing to Mona's obligation to autonomy and her desire to be an adult is meant to provide an intrinsic motivation for her compliance in a birth control routine.

Lifework: "You Have a Job to Do"

In their interactions with each other, staff and participants frame their actions in a way that requires the participant to take ownership over their shared work and establishes social and temporal distance between staff's interventions and the moment of autonomous action. While this carefully constructed framing allows staff and participants to understand their work as distinct, there are times when care and autonomy cannot be disentangled. In these instances, the interpretive power of *lifework* to manage this tension is ever more important. While the project of supported adulthood invites the adult to participate in planning their own support, the process is often met with great anxiety, perhaps because it elaborates the uncomfortable relationship between scrutiny and autonomy that shapes their lives.

During his ISP meeting, Daniel implicated his job coach in his "incarceration," yelled at his mother, and was generally in a sour mood. After the meeting, Elizabeth, his program specialist, confronted Daniel about his behavior, which was "really inappropriate." Daniel spit on the ground at Elizabeth's feet and said, "Fuck you," before punching a street sign and walking off.

Daniel's life straddles a delicate border between support and care. While there are interventions he needs in order to live independently, framing these practices around goals oriented toward autonomy is forceful. Making these goals with the presence and input of others introduces a level of scrutiny that magnifies this force. Relaying her interaction with Daniel to the rest of the staff, Elizabeth recognizes the tension in the dichotomies that shape her work, "I told him, you are an adult. Part of being an adult is doing things you don't want to do. We need to figure out how to get through this in an easy way. You are coming to these meetings like a child with a tantrum."

A life oriented around the explicit pursuit of autonomy through goals brings with it the weight of staff authority. Staff manage this weight by interpreting goals through a lens of normalized adulthood. Aimed at a diversity of areas, goals are communicated to participants as particularly important for their future employment. By doing this, the program communicates the centrality of work in defining an active adult life; waking up on time and orienting one's day around a "normal" schedule," going to activities to build stamina, RSVPing and "calling in sick" to support meetings are all evidence of a healthy and productive adulthood (and therefore autonomy). Still, goals and suggestions are not innately different from their opposites. As Elizabeth interprets her work with Daniel, she recognizes an inherent tension between support and care: being an adult is being "forced" to do things you don't want to do. As an interpretive frame, *lifework* highlights the ongoing obligations and privations necessary to achieve adult status and locates them in society's normative expectations for adult life.

I encountered this most forcefully when I followed Judith for her ComHab hours with Willa. When we arrived at Willa's apartment, she hid behind the door as she let us in. Judith peered around the door as she walked in to see Willa, wearing a T-shirt nightgown with a Looney Tunes logo, hair framing her face in a ratty mess, "Willa, what is going on here?"

We walk into the room and put our things down on the dining room table. Willa sits on the edge of her bed, feet resting on the frame, arms folded in front of her. Willa's eyes are only half open as she replies to Judith's question with a short, "I'm tired." Judith starts in on a long talk with (or rather at) her, "Willa, it is not okay when you have people coming over, to be in your pajamas. You didn't text me before to tell me that you weren't in the mood to do work and you didn't text Kara either. I'm here. We have to do some work." Interpreting her interventions as work signals that today's activities are goal-oriented. Moreover, today's tasks are Willa's *lifework*; a project of the self, aimed at adulthood.

While Judith is talking, Willa replies in short affirmative grunts. Still, she continues to sit on the bed and refuses to get ready for her day, "I'm tired." "Are you sick?" "No." "Okay, then that is no excuse. I'm tired too, but I knew that I had to be here at 8:30, so I got up and I got myself ready."

Judith and Willa stare at each other as if it is a contest to see who will break first. "Look, you can't do this if you have a job… say, 'I'm tired,' but then not tell anybody… and you want a job. Even if I am not here, you still have to get up and get ready for your day." Willa stares blankly straight ahead and Judith turns to another tactic, calling Willa's program specialist. Kara doesn't pick up right away and Judith suggests that Willa call her parents to tell them she is not feeling well. "If they say it's okay, I will leave, but I have a feeling that they are going to be upset." Willa declines, apparent only by her reluctance to move from her position on the bed. "Willa, you can't go back to bed… let's just try to get up and get ready. You can do it slowly." "That's what I'm about to do [go back to bed]." "Willa, you have been so good lately… what's wrong today?"

Willa shrugs her shoulders and Judith starts in on a string of reasons for getting up and ready: "It's not too much to do… You have a vacation coming up to rest… You have the whole afternoon to do whatever you want… You knew I was coming, this is not a surprise… Even last week, you had [menstrual] pain and still you did some work." Willa doesn't answer but continues to grunt with her arms folded in front of her chest. Soon, the phone rings. Willa waves it off, "It's probably just a friend." Judith knows better. Assuming that it is Kara, she encourages Willa to look at the phone. Willa picks up the phone, looks at it, "Oh, it's Kara," and puts it back face-down on the bed. Judith scolds her with an incredulous tone in her voice, "Answer it, Willa!" Willa shrugs her shoulders, "I don't feel like it." "Willa, you have a job to do and if you can't do your job, you have a boss and that's Kara." Here, Judith explains Willa's work as an obligation she can't shrug off, not because of its importance for her personal project of adulthood, but because it is given to her by an outside authority on her life.

Judith's shift between these two meanings of work illustrates the complicated nature of *lifework*. The work of daily life is both a project of the self through which individuals discipline their own actions as evidence of their adult status, and an obligation to autonomy imposed by those around them. The obligation to *lifework* is complicated further by the fact that Willa's work is tangled up with the terms of Judith's employment, in which the vagaries of Willa's daily life—"bad days," drowsy morning, emotional setbacks—are reframed as failure; Willa's failure to progress toward autonomy and Judith's failure to engage Willa's goals, the criteria on which the State reimburses MTIC for ComHab support.

For Judith, Willa's daily life is a job she must do even if she is not motivated. Not only is her current day-to-day life a job, it is preparation for formal employment: "If someone were to ask me now whether you are ready for a job, I would say no." Judith picks up her phone to call Kara herself, explaining that Willa refuses to work because she is tired. Kara gives Judith permission to leave and asks her to write an email explaining in detail what happened today. When she hangs up the phone, Judith turns to Willa and explains that she is going to leave. Willa's tone lifts, "Okay." "Don't say that because it's not okay… [This] is your life."

In this interaction, Judith first frames goals as work and compares Willa's obligations to live her life to her own employment. Further, Judith highlights Willa's personal desire to have a job someday and reminds her that future employment is contingent on her ability to orient her life around a normal schedule and to "work" on her goals. Willa's everyday life is work, an obligation. As the coordinator of her care, Willa's program specialist is her "boss" and Willa is only relieved of her work with a dispensation from Kara. While Judith repeatedly interprets Willa's goals as employment, she ends with a warning that highlights the complexity of this—"it's not okay, this is your life"—reminding her that life and work are inseparable.

Discussion

The nature of action is constructed through interpretation and is given meaning when placed in the context of other actions (Emirbayer 1997; Mol 2002; Eyal and Hart 2016). *Lifework* is an interpretive frame (Goffman 1974) that places action in social and temporal context in order to produce a shared understanding of the meaning behind action. Specifically, *lifework* recasts participant dependency and staff intervention as work toward future autonomy. Goals and suggestions are the primary strategies staff at MTIC use to situate their interventions in relationship to participants' actions. While goals place action in temporal context by identifying the object of action as something in the future, suggestions increase social distance between staff intervention and a participant's behavior by placing responsibility for action on the participant. Through this process of interpretation, the autonomous adult emerges as a self-motivated, independent actor in the midst of their dependence on others.

Counter to other analyses of neoliberal institutions that highlight attempts to remove people from dependency, *lifework* is a strategy for interpreting dependence in context. The strength of *lifework* as an interpretive frame suggests that research on neoliberal governance should take more seriously the role of structure in shaping neoliberal rhetorics of self-improvement (Haney 1996, 2010). Research that looks only at coercive practices aimed at socializing people out of dependence may actually conceal the ways in which strategies of social control create boundaries around dependencies. Research on neoliberal governance should also consider more fully the effects of a group's moral status on the localized shape of social control. For example, McKim's comparative analysis of residents at a substance abuse treatment facility shows that institutions sort patients according to their worth based on their health insurance and employment status (McKim 2014). In the case at hand, participants are adults with an enduring disability that is not imbued with stigma to the same degree as other mental impairments (Bagnall and Eyal 2016). In practice, this means that we both expect and accept that people with IDD will remain dependent to some degree throughout their lives. In this context, neoliberal strategies of social control are more complicated; they are both a coercive force and a generous method to interpret autonomy in the midst dependence.

Not only are participants at MTIC different from other populations subject to neoliberal governance, they are also unique within the population of people with IDD. Participants at

MTIC are overwhelmingly white and have moderate to mild intellectual disability. In the state of New York, 61 percent of adult consumers (people who receive services from the state) are white, compared to 72 percent of those nationwide. Thirty-eight percent of adult consumers in New York state live with their parents or in the home of another relative, 35 percent live in a group home with 4–15 people, and only 12 percent live in their own homes. In addition, 71 percent have mild to moderate intellectual disability, a classification identified in the DSM-5 as having an IQ between 36 and 69 and needing moderate or intermittent support in the activities of daily life (compared to 67 percent of the national population of adult consumers). Like a majority of adult consumers in the United States, MTIC participants have mild to moderate intellectual disability, which minimally impacts their day-to-day lives. However, they represent a small proportion of this population of adult consumers in that they live in their own homes and not with parents or in a group setting.

Still, there is evidence that the type of support provided by MTIC is desired by those lingering on long waiting lists for residential services outside the family home (Braddock 1999; Braddock et al. 2001). In New York state, over 11,000 people are on a waitlist for residential services. A majority of those on the waiting list are between the ages of 21 and 35, and the average time on the waiting list is seven years. Seventy-five percent of those on the waiting list have an Individualized Supports Planning Model score of 1 or 3 (indicating low behavioral needs and low to medium direct support needs), mirroring the statewide population of adult consumers who have mild to moderate intellectual disability. While the adults supported by MTIC represent a minority of those individuals who receive services from the state, the type of care they receive is highly valued by families with unmet residential needs. Of those on the waiting list, over 90 percent of caregiver respondents were interested in learning about residential options other than those that provide 24/7 support.

Families at MTIC are able to bypass the residential request list for limited support services by designing and purchasing the specific type of care they have in mind, an option that is clearly unavailable to a majority of adults living with IDD. While the shape of autonomy and responsibility for the self is likely informed by the racial and socioeconomic backgrounds of MTIC family members (Lareau 2011), research at this program can contribute to a broader scope of service provision, especially for adults with minimal support needs who make up a majority of those on residential waiting lists. In addition, the type of autonomy MTIC advocates reflects a very Western, individualistic conception of adulthood that may not be universally valued. However, MTIC does not exist in a vacuum; the support they provide is constructed out of neoliberal logics that specify ethical and professional guidelines for care. With this in mind, I join other scholars in critiquing the obligation to autonomy that informs modern medical practice (Ho 2008).

Conclusion

Staff at MTIC understand their work according to a logic that associates adulthood with autonomy. This orientation is a professional imperative built on a historical project to balance care and autonomy for people with IDD (Bagnall and Eyal 2016). For independent living programs like MTIC, support is also a practical orientation to account for staff's absence in the daily lives of participants. To accomplish the mandates of care, staff transfer the mantle of oversight to participants by appealing to their intrinsic motivation, informed by normalized assumptions about adulthood, to be autonomous. Staff understand the support they offer to participants in direct contrast to care, which they describe as a natural extension of the caregiving responsibilities of families. This private-public divide contributes to a neoliberal ethic of *self*-improvement and individual responsibility. By framing their work according to this divide, staff absolve themselves of responsibility for a participant's success or failure.

Autonomy is a situational and deeply interpretive project. In the context of participants' lives, it is not always possible to choose from a selection of options that represent a full range of autonomous action. Through interpretation, staff reorient work that obviously looks like care to future autonomy, take the weight of their suggestions onto themselves by inviting participants to an autonomous life that looks like theirs, and deflect the forceful nature of goals by framing them as work. These strategies of framing bracket care from the moment of autonomous action by establishing social and temporal distance (Goffman 1974; Bourdieu 1997; Emirbayer and Mische 1998) between the moment of intervention and the actions of participants. I call this interpretive project to account for autonomy *lifework* to highlight the normative expectations of autonomy and productivity that are communicated to participants in the program.

As a practical strategy, *lifework* allows staff to understand their work as distinct from the work participants have to do. Interpretation allows them to negotiate the tension that remains between the scrutiny of intervention and autonomy. It also allows them to understand the obligation to autonomous behavior as situated in normative expectations about what adults do, alleviating the sensation that they are "forcing" participants to act. Other accounts of this neoliberal frame point to the obligation to autonomy as evidence that institutions of social control subvert autonomy when they scrutinize behavior. What I show in this paper is that neoliberal rhetorics can also be an important mechanism for constructing autonomy.

Participants wake up, eat healthily, and are generally productive because this is what normal adults do. Framing adulthood in terms of *lifework* recognizes the weight of normalized adulthood and defines autonomy as a practice of critical reflection and interpretation of this force. Working out this frame is an ongoing negotiation between the givers and receivers of care (Reindal 1999; Mol 2008). This doesn't necessarily involve making dependence invisible, as others have suggested (Rivas 2011). Nor is this a project of interdependence between actors and their carers (Reindal 1999; Korr et al. 2005). Rather, in *lifework* dependence is accentuated in order to frame it as distinct from the moment of autonomous action. Specific moments of dependence are separated from autonomy in temporal and social space and then embedded within the work of future autonomy. Returning to a preliminary question—*how* are individuals autonomous—I offer this: It's a matter of framing, an ongoing and collaborative project to understand relationships and the practices within them in terms of temporal and social distance.

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